

The Demography of Devotion:
Comparing Amish and Hasidic Jewish Religious Responses to Genetic Diseases

A Senior Honors Thesis

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Introduction

As minority religious groups in the United States, the Amish and Hasidim today share a great deal in common in terms of their ideological origins stemming from political turmoil in Europe, their history of persecution prior to arrival in the United States, their motivations for coming to America and their experiences since arrival. Both the Amish and the Hasidic Jews lived on the fringe of European society, and as a result they suffered bitterly at the hands of Europe's religious and political establishments. Early Amish and Hasidic leaders offered alternative ways for their respective faithful to journey spiritually regardless of their social standing. Subsequently, the promise of freedom from such persecution by moving to America was irresistible for both the Amish and the Hasidim, and both populations have flourished in this country since their arrival.

The most compelling similarity between the Amish and the Hasidim, however, is that both groups are socially and genetically closed societies, making them uniquely susceptible to genetic diseases compared to the general population of the United States. While research has focused on the genetic diseases that occur with greater frequencies *within each group*, prior research has not compared genetic diseases across both Amish and Hasidic Jewish populations. Given the many similarities between the two groups, a comparison of how genetic diseases are expressed and how such diseases are regarded within each community serves to broaden our understanding of how societies with restricted marriage markets face such challenges. These are the topics that form the focus of my thesis.

I begin my thesis by discussing each group's origin. With an understanding of the cultural context of each population, I then present the predominant theories regarding the

frequently occurring genetic diseases within each group, and the ways in which genetic diseases have been incorporated into each group's ethnic narratives and collective experiences. To do this, I draw on extant sociological and medical research about each population as well as primary sources of information, including publications from the Amish community. Although I tried to access similar primary sources from the Hasidic community in New York, my attempts were unsuccessful because I lacked sufficient connections within that community. The results of my research show that there are numerous similarities and differences between the ways each population approaches genetic diseases within their communities, and that religious principles play a decisive role in shaping such communal responses in both Amish and Hasidic Jewish populations.

Origins of the Amish Anabaptists

The Amish are inheritors of the Anabaptist legacy begun in Europe after the Protestant Reformation, a period of great religious and political upheaval that swept Europe during the 16th century C.E. (Hostetler, 1993). Led by Martin Luther, the Protestant Reformation was rooted in the belief that an individual could establish a relationship with the divine on his own, instead of having to rely on church clergy -- a belief that questioned the monopoly that clergy held on such a relationship and hence challenged their power. While this debate sent shockwaves through Christian Europe, it did not go far enough for the Anabaptists, who advocated for important addenda to the relationship between the individual, his religion, and the state. Such reforms, including complete separation between church and state, and adult baptism instead of infant baptism, were considered heretical in those days even by most Protestants. These first

addenda were introduced in the Schleithem Articles of 1527, published at one of the first secret conferences of European Anabaptist leaders. From this point on, persecution of Anabaptists increased dramatically, as Catholics and Protestants alike actively hunted Anabaptists, forcing them to live in obscurity and secrecy (Hostetler, 1993). Although Anabaptists were occasionally given assistance by non-Anabaptist *treuherzige* (true-hearted), imprisonment, torture and death were a grizzly reality in a world turned upside-down by religious turmoil (Kreps, Donnermeyer and Kreps, 2004).

Although the Amish are inheritors of the Anabaptist legacy, they did not emerge as a distinct Anabaptist group until the late 17th century C.E. By this time, the largest concentrations of Anabaptists were located in Switzerland, the German principalities, and the Netherlands. Swiss Anabaptists, commonly referred to as the Swiss Brethren or Swiss Mennonites after influential 16th Anabaptist thinker Menno Simons, had experienced a great deal of persecution by local authorities and had migrated north to the Netherlands where the environment was far more tolerant. With the influx of Swiss Mennonites into Northern European Anabaptist life, however, a conflict of purpose arose between the two communities. As a result of the greater degree of acceptance that Anabaptists in Northern Europe experienced, they had developed a more stringent attitude towards methods of avoiding being yoked to “the world,” particularly in regards to *Meidung*, or the practice of avoiding deviant members of their community as a means of imposing social sanctions (Hostetler, 1993). In contrast, the Swiss Brethren, who brought stinging memories of persecution in Switzerland with them, saw less need to shun deviant members of their community in order to maintain a cohesive Anabaptist identity. This clash of ideology reached its zenith in 1693, as Jacob Amman, a powerful but controversial representative

of the Alsatian Anabaptists, excommunicated Hans Reist, a senior Swiss elder who advocated for far less stringent policies of avoidance. From this point, those who remained faithful to Amman's ideals came to be known as "Amish," departing permanently from their less orthodox Mennonite cousins (Hostetler, 1993).

Amish immigration to the United States began in the colonial era, when Pennsylvania Governor William Penn actively recruited oppressed populations in the Rhine River region of Western Europe in the hopes that they would contribute to the nascent American economy. Eager to flee a continent that had treated them with thinly veiled hostility at best and murderous persecution at worst, the Amish, along with their Mennonite cousins, capitalized on the opportunity. The first certifiable documentation of Amish immigrating to the United States dates back to 1737, and Amish emigration from Europe continued in a steady stream well into the 19th Century (Hostetler, 1993). By the early part of the 20th Century, there ceased to be any Amish living outside of the United States and Canada, where they eagerly took the chance to take up the agricultural lifestyle so central to their culture today. Once in America, however, the Amish still strove to maintain a lifestyle inspired by the Christian Bible's injunction to not be yoked to the world of the profane (Kreps, Donnermeyer and Kreps, 2004), creating a unique cultural juxtaposition to a rapidly modernizing and urbanizing American society.

Today, Amish communities flourish across the United States and practice varying degrees of strictness in their separation from modern society. The focus of this research will be on the division of Amish known as "Old Order," who tend to be more conservative in their worldviews and marriage patterns (Hostetler, 1993). As a result of unprecedented population growth since 1900, there are currently close to 400 Amish

settlements in North America, with a total population of roughly 220,000 (Associated Press, 2008). The largest concentrations of Old Order Amish in the United States are found in Holmes County, Ohio, and Lancaster County, Pennsylvania, respectively. Certain issues regarding the genetic legacy of the Amish arise alongside this population boom, however, as the Amish have also inherited an extremely limited gene pool from their ancestors. The determination of the Amish to maintain their separation from the modern world has significant consequences for the health and well being of the Amish. Today's Amish are descended from only 15 – 20 different families, meaning that there is a much higher likelihood for genetic mutations to remain and become expressed within the population (Hostetler, 1993). This consequence of history shares much in common with that of the Hasidic Jews, whose similar history has resulted in very similar genetic issues.

Origins of the Hasidic movement

The origins of the Hasidic movement in Judaism share much in common with the origins of the Amish. Just as the Amish stem from pietistic movement based in Christianity during the 17th and 18th centuries in Europe, Hasidic Jews in the United States and many other countries belong to “the pietist movement that originated among [the] 18th century East European Jews” (Rubin 1964). At its heart, the Hasidic movement began as a “fundamentalist movement whose aim was to restore the religion to its pristine splendor, and to revitalize religious values which had lost their potency” (Samet, 1988). Since the time of its inception up to the present, the Hasidic movement has maintained a unique position within the scope of modern Judaism, as its members adhere to a strict,

largely inwardly focused interpretation of Jewish law and practice while also negotiating their many internal factions.

The movement began in Eastern Europe in the early decades of the 18th century C.E, in the context of social upheaval in Europe and the failed messianism of Shabbetai Zvi a century prior, which was a particularly painful experience for Jewish communities both within and outside of Europe. A charismatic Jewish leader of Turkish origin who claimed to be the long-awaited Messiah, Shabbetai Zvi attracted a large and enthusiastic movement amongst Jews from Europe and elsewhere in the late 17th century, only to then devastate them spiritually by converting to Islam and renouncing his views before his death. While messianic movements are in no way foreign to Judaism, Shabbetai Zvi's messianism involved the infusion of kabbalistic mysticism into traditional Jewish thought while also coinciding with anti-Jewish pogroms in Poland in 1648, giving the movement a more universal dynamism than previous messianic movements (Scholem, 1973). The post-Sabbatean period thus left Europe's Jews reeling in a spiritual quandary, as their bitter disappointment was tempered by their lingering desire for the enthusiasm and ecstatic personal religious experience with which Shabbetai Zvi had infused them (Dimont, 2004). This passion, heavily inspired by the emergent mystical trends of the 17th century, paved the way for the Hasidic movement to arise during the 18th century under the leadership of Rabbi Israel ben Eliezer.

Israel ben Eliezer is as enigmatic a figure in Jewish history as Jacob Amman is in Amish history. While Amman never proclaimed to be the Messiah in the way that Shabbetai Zvi did, ben Eliezer is considered a messianic figure as he enjoyed a following comparable in its devotion to that of Shabbetai Zvi. Born around 1700, he was active in

Poland and Russia and had a reputation for being a healer or “ba’al shem”. For this reason, he is referred to as the “Baal Shem Tov,” or “the [Good] Healer” amongst both Hasidic and non-Hasidic Jews (Lenowitz, 1998). While many of the specific details of Israel ben Eliezer’s life are unclear, accounts of his life testify to his heightened spiritual state and mystical capabilities. His most significant contribution to the development of the Hasidic movement is his “aspiration for personal faith, for a Torah of the heart, for religious perfection of the individual, within the context of the nation but for the sake of the individual” (Dinur, 1978). This belief came to be central to the Hasidic philosophy regarding Jewish practice, as access to a relationship with God was thus opened to not only those with the means to study in the largely urban centers of Jewish learning but also to those rural, poorer Jews who lacked access to such networks (Dimont, 2004). Although ben Eliezer’s message of a personal, mystical connection to God spread like wildfire throughout Eastern Europe during the 18th century, the Hasidic movement quickly fractured after his death. While ben Eliezer had been the spiritual leader of the movement during his lifetime, after his death leadership became condensed at the local rabbinate level throughout areas of Europe with active Hasidic centers. Rivalries quickly emerged between these disparate groups, each of whom followed the overall Hasidic doctrine yet adhered to the particular views of their own spiritual leader or *rebbe*. As a result, within the Hasidic movement today there are numerous branches of followers, all of which proclaim allegiance to a specific *rebbe* (Mintz, 1994).

Jewish communities in Europe experienced periods of both prosperity and intense persecution in the centuries following their initial arrival to the continent. However, conditions in the centuries following the rise of the Hasidic movement were such that

Jews began immigrating to the United States in massive numbers, hoping to capitalize on the same promise of security and prosperity that William Penn had offered to the Amish. While non-Hasidic Jewish immigration to the United States reached its peak in the late 19th and early 20th centuries, Hasidic Jews by and large remained in Europe until the years before and after World War II. The Nazi campaign throughout Eastern Europe was particularly devastating for this population of Jews, and by the time survivors arrived in the United States their numbers were only a fraction of what they had been before the war (Mintz, 1994). In the years since World War II, however, Hasidic communities have flourished rapidly in the United States, particularly in the New York City area, where their numbers are highest and their community is most active. While exact population figures are difficult to obtain due to their reluctance towards divulging sensitive demographic statistics, it is estimated that there are roughly 200,000 Hasidic Jews in the United States (PBS, 1998).

One of the most significant similarities that the Hasidic Jews share the Amish is that both are closed populations resulting from their patterns of endogenous marriage that stem from relatively inward-looking worldviews. Centuries of demographic and cultural isolation have affected the gene pools of each group so that members of each group today are disproportionately susceptible to certain genetic diseases that are less commonly expressed in the wider American population. This intersection of religious endogamy and social closure makes the Amish and the Hasidic Jews worthy of comparison, so that the dynamics affecting their travails with genetic disease may be better understood.

Background: Persistence of Genetic Diseases within each community

When considering the genetic diseases that are prevalent within these two populations, scientists point to a number of phenomena that have significantly impacted the genetic diversity of each group because they have, having occurred over a great enough span of time. One such phenomenon is genetic drift or founder effect, wherein a population relocates to a new area and eventually becomes genetically distinct from the larger host population as a result of the DNA from the few founders of that population having been preserved (Goldstein, 2008). The Amish today are descended from a small number of “founding” families whose DNA, after centuries of endogenous marriage and self-enforced exclusion from the gene pools of the larger populations surrounding them, has been passed down to the present generation. For the Amish, the current result of this trend is dramatic: in the three largest Amish settlements in the United States, five surnames account for over half of the total population, a trend that has similar manifestations throughout a majority of Amish communities today (Hostetler, 1993). Just as Amish surnames are concentrated in specific geographic regions, certain genetic diseases common to the Amish also occur with higher frequency in specific Amish population centers. I will discuss this trend in greater detail in my discussion of the genetic diseases that occur with greater frequency within Amish populations.

While this trend is not quite as prevalent amongst Hasidic Jews thanks to their relatively wide dispersal throughout Eastern Europe prior to their arrival in America, genetic drift has also impacted this group’s tendency to preserve genetic mutations among its members so that they too are prone to certain genetic diseases (Goldstein, 2008). Key among these diseases is Tay-Sachs disease, a particularly devastating

condition whose origins have been traced to specific towns and regions in Eastern Europe. The disease is rarely reported among Jews whose origin is beyond this isolated geographic area, however (Kolodny, 1979).

Another theory that scientists have traditionally used to explain the prevalence of genetic diseases amongst closed populations is that of selection. Selection theory posits that specific genetic mutations have persisted amongst certain populations because they are in some way beneficial to that population's survival. Perhaps the most famous example of this is the ability of those carriers of sickle-cell disease to resist many strains of malaria. According to selection theorists, the genetic diseases to which the Amish and the Hasidic Jews are more susceptible could have possibly remained in their populations because they allow for another more favorable trait to be expressed. In a rather controversial study, some anthropologists have suggested that the presence of Tay-Sachs among the Ashkenazi Jews is correlated with an increased prevalence of higher levels of intelligence, making it a deadly but useful mutation to preserve within that population's DNA (Goldstein, 2008). While such a theory is nearly impossible to prove and risks legitimizing stereotypes about Ashkenazi Jews through speculative research, the theory of selection is certainly worthy of further research if scientists are interested in finding ways for these groups to manage such diseases (Goldstein, 2008).

As previously suggested, cultural values and history also play an important role in influencing the genetic makeup of communities such as the Amish and the Hasidic Jews. The two groups share a devout commitment to their religious texts, the Christian Bible and the Torah respectively, and each relies upon a mechanism for maintaining social integration within the context of their religious beliefs. For the Amish, the *ordnung*

serves as such a mechanism, as it is the social covenant between all Amish baptized into the Church and between the community and its religious commitments, thus influencing every decision made within the community (Kreps, Donnermeyer and Kreps, 2004). The Hasidim live stringently by Jewish law as extrapolated from the Torah and the teachings of Judaism's rabbis and scholars, or *halakha*, and rely on it to inform every decision in their communal lives. Similar to the *ordnung* in this respect, *halakha* forms the backbone of the Hasidic community and provides community members a means by which they can maintain the integrity of their community through consensus of belief and practice (Mintz, 1994).

Such strict adherence to religious law requires a significant amount of voluntary separation from the larger community on the part of both communities. For the Amish, such an edict comes from Romans 12:2, wherein they are encouraged to remain unchained to the world (Kreps, Donnermeyer and Kreps, 2004). For the Hasidim, the call for preservation of communal integrity is echoed throughout Jewish traditional texts, including the words of Ezra the Prophet (Goldstein, 2008). Such practice inevitably leads to endogenous and even consanguineous marriages amongst the Amish and the Hasidic Jews, which has contributed significantly to the prevalence of certain diseases amongst the two populations. In addition to the active measures that each group has taken to ensure its separation from the modern world, the Amish and the Hasidic Jews each share a history of intense persecution that has resulted in a degree of separation that has been involuntarily imposed on them. For the Amish, such exclusion came as the result of the bitter persecution from both Catholic and Protestant governments during the period of Reformation (Hostetler, 1993); for the Hasidim, their separation from the modern world

was sharpened by centuries of equally bitter torment at the hands of numerous European governments (Mintz, 1994).

The commonalities both groups share in terms of their marriage patterns, cultural history and worldviews have impacted their genetic legacies. It is possible to understand the significance of inheritable disorders within the context of culture, genetics and history. In the following sections I discuss the diseases that occur with greater frequency in each of these populations than in the general American population that surrounds them.

Genetic Diseases Common among the Amish

The Amish are an ideal population in which to study the pedigree of genetic diseases because their society is almost completely closed off from the rest of American society, and they have also made painstaking efforts to keep accurate genealogical records. Thus, while there are currently no remaining Amish populations in the geographic regions in Europe where the Amish originated, sufficient data exist to trace the migration of both their ancestors and their ancestors' genetic diseases to the present day. This genetic treasure-trove was left untapped until the 1960s, when researchers began studying the Amish population in-depth (McKusick, 1978). Since then, it has become evident that Amish populations in the United States are, like their Hasidic counterparts, far more likely to exhibit certain genetic traits, especially genetic diseases, when compared to the general American population. Victor McKusick, one of the pioneers of genetic research on the Amish, has noted that "the Amish consider themselves a 'chosen people' or 'peculiar people,' just as do the Jews. Ethnic solidarity, i.e. genetic distinctness, and religious separateness are interdependent" (1978).

Just as it is necessary to highlight the ethnic distinctions amongst today's Jewish populations so we can understand the nature of the genetic diseases prevalent amongst Hasidic Jews of Ashkenazi descent, genetic diseases affecting the Amish also cannot be understood without an explanation of the role that founder effect has played in influencing the geographic distribution of such diseases. Because of the closed nature of Amish populations, particularly the Old Order Amish, many of the diseases that are common amongst the Amish today can be traced back to a single ancestor who carried the mutation to the United States (Hostetler, 1993). This trend is reflected prominently in the clustering of Amish surnames by geographic location, signifying the formation of demes, or inbreeding, isolated communities - for example, the surname Stoltzfus accounts for 25% of the families in Lancaster County, Pennsylvania (Hostetler, 1993). After decades and eventually centuries of reproductive isolation, these genes became prevalent in the local populations where the original carrier settled. As a result, certain diseases appear in different Amish populations throughout the United States; Ellis van – Creveld Syndrome is one such disease, as it has an “unprecedentedly high frequency ... in the Lancaster County [Pennsylvania] Amish” (McKusick, 1978). For the purpose of this study, two of the most common genetic diseases are of particular interest.

Ellis – van Creveld Syndrome is the first of these commonly occurring diseases. Presently, it occurs in 1 per 60,000 individuals in the general American population but in 1 per 200 Old Order Amish (Chen and Laufer-Cahana, 2007) (Figure 1). Nearly one third of affected individuals dies within two weeks of birth and half of infant cases die as the result of congenital heart defects (Hostetler, 1993). However, most individuals with Ellis – van Creveld Syndrome survive past infancy if the symptoms are treated early, and these

generally have a normal lifespan (Chen and Laufer - Cahana, 2007). Children born with the disease exhibit polydactyly (extra fingers and toes) and pronounced dwarfism (Hostetler, 1993). Currently, the carrier rate amongst this population is nearly 13%, making issues of treatment and prevention particularly relevant. (Chen and Laufer-Cahana, 2007). As previously mentioned, this disease occurs almost exclusively amongst the Lancaster County, Pennsylvania Amish community, and nearly all cases can be traced back to Samuel King and his wife, who immigrated to America in 1767 (Hostetler, 1993).

Another genetic disease that occurs with a higher frequency amongst Old Order Amish is the blood disorder Pyruvate kinase deficient hemolytic anemia. It has been observed almost exclusively among Amish communities in Mifflin County in central Pennsylvania. This disease is fatal within the early years of life if not treated, as the anemia it causes in affected individuals is particularly severe among the Amish. Furthermore, research has shown that a splenectomy provides great benefit to those affected by the disease, rendering the disease "into a compensated anemia consistent with good health." Another result of founder effect, this disease can be traced back to "Strong Jacob" Yoder who immigrated to the United States in 1742 (McKusick, 1978).

Genetic Diseases Common in Hasidic Jewish Populations

To understand the nature of the genetic diseases that occur more frequently within Hasidic Jewish communities than in other communities, it is important to understand certain important demographic trends that are present among today's Jewish communities as a whole. For the purpose this paper, two of the three distinct ethno-cultural groups that encompass Jews today are addressed. Sephardic Jews, or Sephardim, are the descendants

of Jews that migrated to Spain, Southern Europe and North Africa after the destruction of the Second Temple in Jerusalem by the Romans in 70 C.E. Ashkenazi Jews, or Ashkenazim, are the descendants of Jews that migrated to Western, Northern and Eastern Europe during the same historical period (Dimont, 2004). The third group, Mizrahi Jews or Mizrachim, includes those Jews that settled communities in the Middle East and Asia at the same time that Sephardim and Ashkenazim were settling in Europe and Africa, but they will not be discussed in the context of genetic diseases. While each group has developed unique predispositions towards certain genetic traits over time as a result of the degree of how endogenous their marriage practices were, those of the Ashkenazim will be the focus of this paper, as this is the community to which the Hasidim belong.

While genetic diseases amongst the Amish have largely been attributed to founder effect, scientists theorize that genetic drift and selection have played a more significant role in shaping the genetic legacy of the Hasidic Jews. However, as previously noted, different genetic diseases amongst the Amish are concentrated in different communities as a result of founder effect, and this same dynamic does appear to have affected the Jews as well since their dispersal in 70 C.E, albeit on a much larger geographic scope. After millennia of endogenous marriage patterns, geographic dispersion and a significant degree of isolation from surrounding non-Jewish communities, Jews of Ashkenazi and Sephardi descent all exhibit tendencies towards certain genetic diseases. The trend is particularly acute among Ashkenazi Jews, as they are predisposed to be carriers of roughly 40 inheritable conditions (Goldstein, 2008). A number of these conditions are chronic, fatal diseases. Hasidic Jews, as a result of their Ashkenazic background, fall into this category and have struggled bitterly with these

conditions over the years. Because this thesis aims to address the ways in which individuals with such diseases are treated in their respective societies, it is important to consider the degree to which diseases prevalent in each community are fatal. This is especially important among the Hasidic Jews. As I discuss later, fatality and treatment have intersected, often controversially, in the debate among Hasidic Jews over how to best manage the presence of genetic diseases in their communities.

Gaucher disease is an autosomal recessive lipid storage disorder that occurs with a greater frequency amongst Ashkenazi Jews than in nearly any other group. First recognized in 1882 by Phillipe Gaucher (Beutler 1979), the disease occurs in roughly one in 450 Ashkenazi Jews while only occurring in one in 100,000 Americans (MazorNet 2009). Furthermore, the carrier rate for Gaucher disease amongst Ashkenazim is one in ten, making the disease a serious concern for the Jewish community (MazorNet 2009) (Figure 2). It is characterized by a massive accumulation of the glycolipid glucocerebroside, in the spleen, liver and bones as a result of a lack of glucocerebrosidase, glucocerebroside's regulatory enzyme. Although there is no cure for this disease, several therapies and treatments are available to improve and lengthen the quality of life of affected individuals, including enzyme replacement therapy (Beutler, 1979). The symptoms of Gaucher disease are diverse, including anemia and easy bruising, and can appear at any point in an affected individual's life. The disease is most dangerous when it appears in infancy, but individuals with the disease can live anywhere from six to 80 years depending on the severity of symptoms and the effectiveness of treatment (MazorNet, 2009).

The most deadly of the genetic diseases common in Ashkenazi populations is Tay-Sachs, an autosomal recessive lipid processing and storage disorder that becomes apparent in infancy and is always fatal (Kolodny, 1979). Warren Tay, a British ophthalmologist, and Bernard Sachs, an American physician were the first to recognize the characteristics of Tay -Sachs disease in the 1880's. Children born with Tay-Sachs typically exhibit normal development at birth, but signs of retardation and disability becomes quickly apparent soon after (Wailoo and Pemberton, 2006). As the disease progresses, affected children experience seizures and gradually lose the ability to see and to hold their head in an upright position. After the age of two, children with Tay-Sachs remain in a vegetative state and require constant care and nursing. Most affected individuals die within the first years of life, usually as the result of complications from pneumonia or another infection. In the century since its identification, no successful treatments for Tay-Sachs disease have been developed short of therapies intended to alleviate its debilitating symptoms (Kolodny, 1979). There has been a great deal of research dedicated to the disease, however, and understanding of the disease among researchers has improved dramatically.

An overwhelming majority of cases are reported amongst Jews of Ashkenazi descent. More specifically, Kolodny notes that "an unusually high percentage of the grandparents of children with Tay-Sachs disease were born in the Polish-Russian provinces of Grodno, Suwalki, Kvonon, Latvia and neighboring Byelorussia" (1979). For the ancestors of these individuals, the carrier rate for this disease is roughly ten times higher than that of the general U.S. population - currently 1 in every 27 Ashkenazi Jews are carriers for the disease, while the carrier frequency in the non-Ashkenazi Jewish

general population is only 1 in 250 individuals (MazorNet Tay-Sachs 2009) (Figure 3).

This trend suggests the influence of a founder effect, as Jews who lived in this area lived in almost complete genetic isolation from non-Jews and thus brought the disease with them out of Eastern Europe. Many Jews from Western Europe are also carriers for Tay-Sachs, but the prevalence among their members is proportionately lower (Kolodny, 1979).

Despite the prevalence of genetic disease in both populations and the close geographic proximity of their countries of origin, there do not appear to be any genetic diseases that are common in both the Old Order Amish and the Hasidim. This is likely the result of the fact that the two groups are not only genetically isolated from the general American population but from each other as well by default. The strict cultural boundaries separating the two groups prevent any genetic mixing, allowing for both founder effect and selection to occur within each group independently of the other. Most importantly, after centuries of isolation and genetic preservation, the Amish and the Hasidim have each become uniquely susceptible to particular genetic diseases compared to the general American population. After a discussion of such diseases and the genetics behind their transmission and preservation within each society, I now turn to a discussion of how the nexus of religious values, cultural practices and modern science influence the treatment of affected individuals in both populations.

Country Lore and Special Children: Genetic Diseases in Amish Communities

The Amish treat community members with genetic diseases in a manner informed by their strict religious beliefs and their sense of collective historical experience. Being a

pietistic community whose means of maintaining social integration are informed almost entirely from the teachings of the Christian Bible, the Amish regard individuals within their communities that are affected by genetic diseases in ways that they believe to be in harmony with their religious views. The Amish share outlooks similar to those of the Hasidic Jews regarding more controversial methods of dealing with genetic diseases, especially in their opposition towards abortion. Where the two populations differ, however, is in the views they hold regarding preventative measures, especially genetic testing.

Although the Amish population in North America today comprise over 200,000 people, their high fertility levels means that their population is doubling in size every 20 years. Only 20 years ago their population was just half the size it is today (Kreps, Donnermeyer and Kreps, 2004). As a closed society with a relatively small population size, there is a high degree of consanguineous marriage occurring within today's Amish communities. Even though the Amish no longer condone marriages to first cousins, as they did in the past, it is not uncommon for marriages between second cousins to occur (Melton, 1970). Despite their disdain for higher education, particularly regarding science and evolution, the Amish are aware of that such marital practices increase the likelihood that a child born from the union will be either a carrier for, or affected by, a genetic disease. Careful maintenance of family pedigrees and close-knit community ties have allowed the Amish to be astute observers of their own condition. The Amish have also incorporated discussion of problems resulting from inbreeding into the debate over the role of a higher power in dictating the course of their lives. In the words of Joseph Stoll, former editor of Pathway Publications, a popular Amish news magazine,

Certainly, God can and does allow abnormal children to be born to parents who are related, and to parents who are not. In some instances He may well have a special reason for letting such a child be born to certain parents. In any case[,] it is God's will insofar that He allows it to happen (Melton, 1970).

Stoll also reflects a large portion of the views of his Amish readership when he states that "we were always taught that if such a child was born to us, it would be because it was God's will. So perhaps He ... wants to draw us nearer to Him through such children" (Melton, 1970).

Because of their view that the manifestation of genetic disease is in some way a divinely inspired occurrence, the Amish recognize the occurrence but do not necessarily view it as a "problem" that needs to be solved by either genetic testing or changes in their family building behaviors. They have, however, gone to great lengths to integrate affected individuals into their entire social mechanism. Kinship networks between affected individuals, who are largely referred to as "special children," are an effective way of providing support and awareness to Amish families throughout America. This dynamic is particularly strong thanks to the presence of articles in popular Amish publications such as *Family Life* (Melton, 1970) and *The Diary*, wherein Amish communities are encouraged to be understanding and compassionate towards individuals with genetic diseases in all areas of life, from education to farm work. This sentiment is reflected in obituaries written for children that die of genetic diseases, where it is normal to say that the child was "a special child who was ill a lot" ("Obituaries", 2007). For those who survive past infancy with genetic diseases, actual employment opportunities for

people who suffer from such conditions as Ellis - van Creveld syndrome dwarfism are limited due to the rigorous physical labor predominant in the Amish economy, Amish families and communities negotiate the boundaries of their ordnungs as effectively as they can (Melton, 1970).

In addition to these written venues for imploring upright conduct towards individuals with genetic diseases, the Amish also relay stories amongst each other that serve as warnings to those who do not treat such people with respect. These colloquial narratives are firmly rooted in the Amish commitment to upright behavior and the presence of a higher power in every aspect of their lives; if they act disrespectfully towards a disabled person, such misfortune could befall them as having affected children themselves or acquiring a similar deformity to that person they may have taunted. The Amish saying "Gott lost sicht nicht spotton" (God is not mocked) reaffirms such beliefs (Melton, 1970).

While the strong influence of folklore and the use of parables as modifiers of conduct are a strong presence in the Amish community, the Amish have also embraced the wisdom of the medical community to help them deal with genetic diseases in their population. Victor McKusick's seminal research on Amish genetics laid the groundwork for understanding genetic diseases in the context of their society and allowed the Amish to become more aware of their situation (1978). In stark contrast to their Hasidic counterparts, the Amish are adamantly opposed to the types of premarital screening programs that have been instrumental in preventing the occurrence of genetic diseases. In a study comparing Amish, Mennonite and, Hutterite attitudes towards testing for cystic fibrosis (CF), Miller and Schwartz (1992) found that the Amish were far less likely than

their counterparts to agree to prenatal genetic testing. Not surprisingly, they also appeared to be less accepting of aborting a fetus known to have CF. There appeared to be some ambiguity, however, among the Amish respondents as to whether or not they would limit the number of children they had if they knew that they were a carrier for a genetic disease. Furthermore, Amish attitudes concerning the acceptability of marriage between carriers were also ambiguous, reflecting either personal indecision or discomfort answering the question (Miller and Schwartz, 1992). Given the great deal of deference given to God in determining the reproductive outcomes of Amish marriages, such reluctance towards testing could possibly be fueled by reluctance towards interfering with God's intentions.

Despite efforts made by the Amish to sequester themselves from the modern world, this unique population has actively engaged the scientific community in recent decades in order to help affected community members cope with genetic diseases. Dr. Holmes Morton's Clinic For Special Children in Strasburg, Pennsylvania has been providing treatment for those within the Amish community that suffer from genetic diseases since Dr. Morton founded it 1989. This clinic treats individuals who suffer from more than 100 different types of genetically inherited conditions that range widely in their degree of severity (Clinic for Special Children, 2008). Whereas Dor Yeshorim's focus in treating genetic diseases began with premarital genetic testing due to the inevitable fatality of Tay-Sachs disease, the Clinic for Special Children emphasizes testing children for diseases before the most severe symptoms emerge in order to prevent early fatality and improve quality of life. This approach seeks to minimize the damage that such genetic diseases can cause for the clinic's predominately Amish patients,

emphasizing the higher preference of the Amish for treating genetic diseases over preventing births that might yield potentially fatal conditions. In addition to treating patients affected with genetic diseases, the clinic, 90% of whose patients do not invest in health insurance, also actively engages in genetic research and education programs so as to promote awareness among both the scientific and Amish communities (Clinic for Special Children, 2008).

For a community that goes to great lengths to separate itself from contemporary society, the Clinic for Special Children provides the Amish with necessary medical care while still respecting their unique cultural mores. A poignant example of this is the clinic's efforts to gain sufficient funds to cover their operating costs without having to put Amish patients under pressure to buy health insurance, which the Amish view with particular disdain (Clinic for Special Children, 2008). Since its founding, the Clinic for Special Children prides itself on its ability to provide such a crucial service to Amish communities all across North America, and in doing so they have been able to create a bridge between the Amish world and the modern one.

Thus, while genetic diseases will most likely persist within this population as a result of such factors as resistance to genetic screening and prevention, the Amish have found numerous effective ways of integrating affected individuals into their close-knit social fabric. Whether it is through folklore or country medicine, the Amish, like their Hasidic counterparts, rely on a multitude of ethnic and scientific practices in order to navigate the often-muddy world of genetic ailments.

Dor Yeshorim: Intersections of Prevention and Ethics among Hasidic Jews

The treatment of individuals with genetic diseases in Hasidic Jewish communities is informed by both their strong sense of collective historical experience and their strict adherence to Jewish religious law. Because of the devastating effects of Tay-Sachs at all levels of the Hasidic community, as well as the stigma that genetic diseases have brought upon Jewish communities in recent times, efforts at prevention and eradication of these diseases has taken on an urgency not found in America's Amish communities. While the Amish view the transmission of genetic diseases as largely being "in God's hands," the Hasidim have strived to both live in accordance with their religious precepts yet ensure that as few cases of Tay-Sachs emerge as possible. As a result, the Hasidim have established institutions and cultural practices that have allowed them to take greater control over the transmission of such genetic diseases through genetic testing and screening. These advancements, however, have also exposed the community to new ethical dilemmas surrounding such practices.

Because of its devastating fatality and its almost exclusive occurrence among Ashkenazi Jews, the struggle against Tay-Sachs disease has become emblematic of the struggle by the Ashkenazi Jews to define their national narrative in the face of the racialized stigmas historically associated with such diseases. Discovered at a time when Jews were immigrating to the United States in large numbers from Eastern Europe, Tay-Sachs was associated with a group of people that was then considered to be of a separate "race" (Wailoo and Pemberton, 2006 and Goldstein, 2008). Just as stigma had plagued Jewish communities before their arrival to the United States, the identification of a "Jewish" genetic disease threatened to create space for such stigma in the medical and

political realms as well (Reuter, 2006). Since that time, scientific understanding of Tay-Sachs disease has enabled the Jewish community to establish what Wailoo and Pemberton consider "the symbolic connection between Tay-Sachs and Jewish people" that has "made ethnicity and culture a prominent concern shaping the promise of medical innovation" (2006). With the introduction of large-scale genetic testing and prevention programs in non-Hasidic Ashkenazi communities in the 1970's, Jewish communities were able to exercise far more agency over the appearance of such devastating conditions and tie it to their own ethnic narrative.

Although genetic screening and prevention programs began in earnest among non-Hasidic Ashkenazi populations first, the Hasidim added their own solution to the problem of genetic disease by establishing the Dor Yeshorim institute in Brooklyn, New York in 1983 (Wailoo and Pemberton, 2006). Rabbi Josef Ekstein, an ultra-Orthodox rabbi active in New York City, founded the movement as a result of his own family's devastating encounters with Tay-Sachs - his wife had given birth to four consecutive children with the disease, and the immense toll of the ordeal inspired him to use his mobilize his faith to raise greater awareness among the Hasidic community (Goldstein, 2008). Initially, Rabbi Ekstein encountered significant resistance, but gradually his idea gained momentum:

"The point I made was that this was a problem for the entire community, not just for me... At the beginning of Dor Yeshorim we had much opposition ... But the idea caught on...and it gained support from other rabbis. Now testing has become a part of Jewish culture" (Wailoo and Pemberton, 2006).

The success of the Dor Yeshorim program in the Hasidic community has been dramatic. This is largely due to the effectiveness with which Rabbi Ekstein and his associates have been able to combine Hasidic religious values and medical awareness so as to almost completely eliminate Tay-Sachs disease from Hasidic communities in both the United States and in Israel (Goldstein, 2008). One of the greatest obstacles to preventing Tay-Sachs occurrences was the Jewish religious injunction against abortion in all instances except those that endanger the mother's life. As this firmly held belief made prenatal carrier screening irrelevant, Dor Yeshorim adopted the approach of premarital screening. By taking blood samples from ultra-Orthodox high schools and submitting them to an anonymous screening process, Dor Yeshorim allows parents, matchmakers (used commonly in the Hasidic community for marriages) and young people to test the "advisability" of a potential match. When a match is suggested in the community, Dor Yeshorim's record bank is consulted so as to see whether a marriage between the two individuals of interest would result in a child being born with Tay-Sachs disease. If so, the relationship, usually in its seminal days, is discouraged and the match is not pursued. Blood samples are kept strictly anonymous and are identifiable only through a number, so as to minimize the risk of carriers being identified and thus stigmatized (Raz and Vizner, 2008).

The issue of stigma is one that had been particularly troubling for families with individuals affected by genetic diseases. Presence of a genetic disease in a Hasidic family was a source of great concern because of the stigma that it brought upon not only the affected individual but the family as well. Rabbi Ekstein himself noted that "families who had children with genetic diseases...didn't talk about it for fear that their healthy children

would not be able to marry," as the presence of a genetic disease in a family greatly reduced a person's likelihood of finding a suitable marriage match (Wailoo and Pemberton, 2006). Dor Yeshorim's program to prevent Tay-Sachs was thus an enormous success in that it did not disclose the identity of any person involved, whether or not they were a carrier.

Individuals with disabilities, including Down's syndrome and other genetic conditions, in the Hasidic world are treated with a "great deal of acceptance," and they receive attention and special education similar to their Amish counterparts. However, the risk of stigma is still pervasive for many Hasidic families. Lack of familiarity with the mechanisms behind genetic diseases and concern over marriage prospects causes a great deal of trepidation for many Hasidim that wish to avoid entering into a marriage from which a genetic disease could be perpetuated (Raz and Visner, 2006).

Controversy has also arisen in recent years over the ethics of Dor Yeshorim's decision in the early 1990's to expand its genetic screening programs to include non-fatal diseases including Gaucher disease. Hasidic religious leaders had gradually come to accept the Tay-Sachs screening program as permissible within Jewish law, and the scientific community had generally been accepting of the program as being within the bounds of scientific ethics. Premarital screening for non-fatal diseases opened the door for "preventing the birth of babies who had diseases for which there were ... effective treatments, or who carried genes for diseases that might ... manifest themselves only much later in life," causing many to question the limits of genetic screening and its appropriate role within such a pious community. Today, Dor Yeshorim mandates that all clients be tested for Tay-Sachs, Canavan's disease, cystic fibrosis and Fanconi's anemia,

while testing for Gaucher disease is optional. Rabbi Ekstein himself has acknowledged that the drastic steps taken in the past in response to Tay-Sachs, such as aborting a Tay-Sachs fetus, are not applicable within Jewish law, acknowledging a potential limit to Dor Yeshorim's activities (Wailoo and Pemberton, 2006). The debate remains, however, over where to draw the line between controlling one's genetic legacy and accepting the role of chance in shaping one's fate.

Discussion and Conclusion

As closed populations in the United States, the Amish and the Hasidic Jews share a great deal in common. Both groups emerged in Europe at a time of great social upheaval, each offering an alternative pathway for their co-religionists in terms of religious practice and spiritual experience. As a result of the inward-looking worldviews both groups developed plus the intense persecution that subsequently befell them, the Amish and the Hasidim closed their societies off from the greater world. One result of this closure was the emergence of such practices as endogenous marriage. Over time, this dynamic allowed for both founder effect and genetic selection to occur within each population, which enabled genetic mutations and diseases to perpetuate themselves within each group. The frequency of certain genetic diseases occurring within the Amish and Hasidim is often much higher compared to the general American population, and the ways that each group has struggled with such diseases also share compelling similarities.

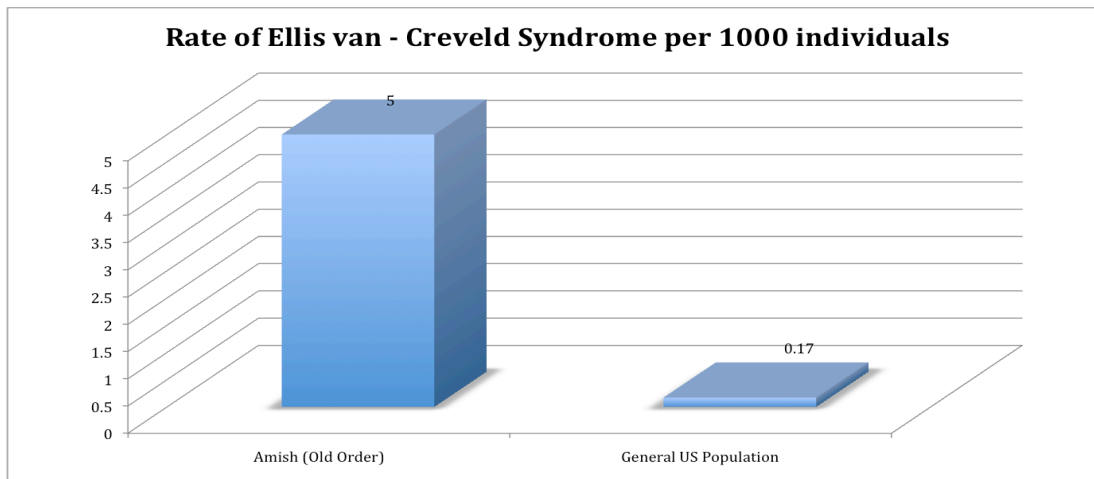
For both groups, religious belief has a strong influence on the communal response to genetic diseases. Hasidic Jews have incorporated genetic testing and prevention measures into their community within the limits of Jewish law, whereas the Amish tend

to avoid preventive measures and focus instead on treating affected individuals within their interpretation of Christianity. Within this context, each population has found a way to engage modern science to suit their needs - for the Hasidim, Dor Yeshorim fulfills this need, as does the Clinic for Special Children for the Amish. As a result, both the Hasidim and the Amish have integrated affected individuals and their communal responses into their ethnic narratives, enabling them to take control of their collective experience within the context of their religious views.

Comparative research such as that which I have undertaken in this thesis broadens our understanding of how the presence of limited marriage markets impacts closed, pietistic societies such as the Amish and the Hasidic Jews. Given the predominant role of religious views in informing their communal responses, this research could be expanded to include other communities in the United States who are also strongly guided by religious principles. Furthermore, as genetically closed societies such as these provide an ideal way to study the transmission of genetic diseases regardless of the role of religious values, my research also has value for non-pietistic communities that are also uniquely susceptible to certain genetic diseases. Expanding the research available about such diseases serves to strengthen our societal responses to them and to exercise greater agency over our genetic legacy.

Appendix

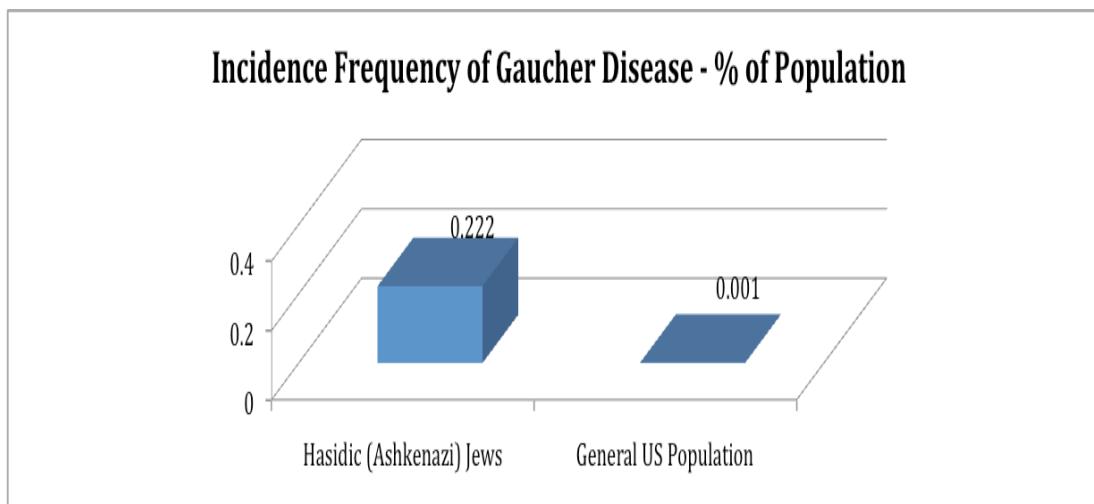
Figure 1 - Ellis - van Creveld Syndrome



Ellis - van Creveld syndrome occurs roughly 50 times as frequently in Amish populations than in the general United States population.

(Data extrapolated from Chen and Laufer-Cahana 2007)

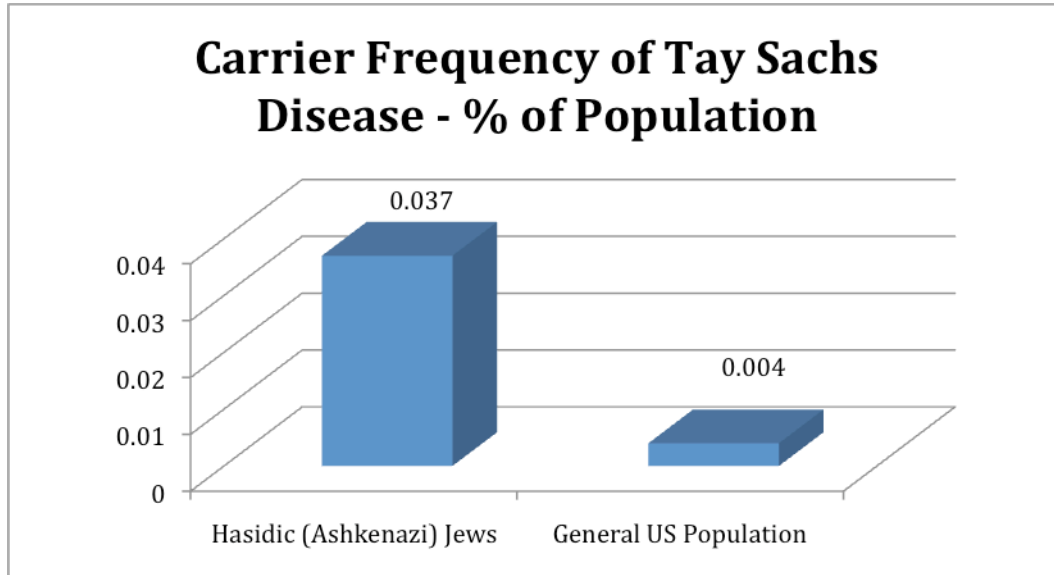
Figure 2 - Gaucher Disease



The incidence rate of Gaucher disease among Hasidic Jews and other Ashkenazi Jews is nearly 200x higher than in the general U.S. population

(Data extrapolated from MazorNet, 2009)

Figure 3 - Tay-Sachs Disease



Hasidic Jews, like all other Ashkenazi Jews, are nearly ten times more likely to be carriers of Tay-Sachs disease than the general U.S. population.

(Data extrapolated from MazorNet Tay-Sachs, 2009)

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